
Comfort and caring at the end of life: Baylor's doula program

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Imagine yourself alone in a hospital room. Your trusted physician has just left after telling you that things are not working out the way he had hoped. The treatment options have been exhausted and you have weeks, perhaps months, to live. Your spouse or life partner died a year ago. If you are lucky enough to have supportive friends and family, you do not want to burden them with long hours at the hospital and add to the stress in their lives. All of a sudden you are flooded with a myriad of emotions, decisions, and questions that need to be addressed. Despite the frequent visits from nurses, technicians, doctors, and therapists, your room feels empty and cold. You dread the long night ahead. You begin to wonder what death will be like and who and what you will need to get through the time you have left. You're overwhelmed and feel very much alone in the journey you are about to make.

Out of a firm belief that no patients at Baylor University Medical Center in Dallas should have to struggle with this experience or die alone, Baylor's Supportive and Palliative Care Service developed and implemented the Doula to Accompany and Comfort Program. After reading a 2004 *New York Times* article, "In Death Watch for Stranger, Becoming a Friend to the End," by N. R. Kleinfeld, one of the team members brought the concept of a doula program to the weekly team meeting for consideration.

The term *doula* has been around for centuries. In ancient Greece, it was used to describe a household servant. It can also mean an individual trained to provide comfort and support to women during labor and childbirth. More recently, it has been associated with those trained to provide support at the end of life.

In 1998, the Shira Ruskay Foundation in New York sponsored a conference on end-of-life issues and care. Dr. Sherwin Nuland, professor of surgery at Yale University School of Medicine and author of *How We Die: Reflections on Life's Final Chapter*, spoke of the Yiddish and Hebrew word for funeral, *levaya*, which means "to accompany." Dr. Nuland emphasized the importance of accompanying the seriously ill through the dying process. Phyllis Farley, chairman of the board of the Maternity Center Association in Manhattan, suggested that well-prepared volunteers could make a significant difference to those who would otherwise die alone. Her suggestion, as well as her assistance in gaining funding for the pilot program, birthed the

Doula to Accompany and Comfort Program at the Jewish Board of Family and Children's Services in New York.

Using private funding, the Jewish Board, in collaboration with New York University Medical Center's Department of Social Services, launched a nonsectarian pilot volunteer doula program in 2001. The program has grown to meet the needs of the dying and the health care professionals who treat and assist them. Well-trained doulas serve those who have limited support from family and friends and provide emotional, spiritual, and social companionship. The program recruits, trains, and supervises volunteers who visit people near the end of life in hospitals, nursing homes, assisted living facilities, and homes. The program also provides consultation and training for institutions interested in developing their own in-house doula programs.

With the support of Dr. Robert Fine, head of Baylor's Supportive and Palliative Care Service and Clinical Ethics Committee, a palliative care nurse, chaplain, and occupational therapist formulated a plan to make the Doula to Accompany and Comfort Program a reality at Baylor Dallas. After an initial 6-week training course and pilot program, the team agreed that consultation with the New York model program would be valuable for further development of the Baylor program. A formal 2-day consultation was conducted by Harriett Feiner, LMSW, the original educator and consultant for the New York program. Representatives from various hospital disciplines were educated regarding successful structuring, modification, and implementation of a doula program to meet patient needs at Baylor. Doula stories and experiences were shared to increase insight and understanding regarding the value and benefits of such a program to patients and families.

For the last 5 years, members of the palliative care team have screened and selected volunteers for the doula program. Volunteers are asked about their views on death and their motivation for taking on the role of doula. Once selected, volunteers are trained by professionals in the stages of death and dying,

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grief and grieving, advocating for patient needs, comfort touch, compassionate presence, active listening, communication strategies, and spiritual and cultural beliefs at the end of life. The doulas provide comfort and companionship to those patients who do not have family support, who feel lonely or abandoned, or whose caregivers are exhausted and desire respite.

“Doulas provide stability in that they are a constant presence for the patient,” said Rev. Marci Pounders, chaplain for the Supportive and Palliative Care Service and coordinator of Baylor Dallas’ program. “Each volunteer is assigned to one patient at a time so that they may concentrate on that person’s needs. They seek to relieve suffering and improve patients’ and families’ quality of life. Often just listening provides the ultimate form of stability.”

Referrals for doulas come from nurses, social workers, and therapists but must be ordered by a physician on the patient’s case. Individual doulas are carefully matched by Rev. Pounders to individual patients and families for the best possible outcome and working relationship. The doula builds a personal relationship with the patient and visits as much or as little as is agreed upon between the two. Regular support groups are held for doulas to process their experiences, debrief, and provide and receive feedback with Rev. Pounders.

Currently, the Doula to Accompany and Comfort Program at Baylor Dallas is limited to inpatients only. The Jewish Board of Family and Children’s Services in New York, however, originally established the program for outpatients but in recent years launched an inpatient model called the Shift Model. The model is designed to increase patient coverage and keep trained doulas actively involved and satisfied with their participation. Rev. Pounders is currently consulting with the director of the Jewish Board of Family and Children’s Services program to adapt Baylor’s program to a similar model. Also, it is the goal of Rev. Pounders and the Baylor Office of Clinical Ethics and Palliative Care to expand the program to all Baylor Health Care System affiliates.

To date, around 80 patients and families at Baylor Dallas have been served by the Doula to Accompany and Comfort Program. Education to increase referrals is ongoing with physicians, nurses, social workers, and others who are instrumental in getting patient and family needs met at the end of life. The following doula journal entries are only a few of the stories the program has to share.

I saw our boy this morning. He’s not got long to live—nods in and out. Prayed that he could find hope in his situation. That made him happy. Nurse said they were looking for a hospice that will take him. He’s got lung cancer and is bone thin. Nice man. Friendly, open to prayer. [The patient later opened up to his doula, talking about his impending death, his life, and how he was coming to a sense of peace about everything that had happened to him.]

Visited with Ms. M. for about 45 minutes. She seemed to be in very good spirits. I rubbed her hands; we watched some television and talked. She asked me to read the Bible to her and I complied. She seemed to like Romans 10:9–10. We always pray together before I leave.

We had a treat! When I entered the room, the hospital’s certified music practitioner was already there playing very soothing music for Ms. P. This seemed to really relax both of us! The musician spoke to her in a very calm voice, helping her to not focus on her pain. You could see the calmness come over Ms. P! She played for quite a while; afterwards we both thanked her, because I had benefited from her music as well! After she left, Ms. P. told me she is just so grateful to be making progress and wants to get better. I encouraged her not to give up and keep her eye on the big picture. She asked me if I had any gum, as she likes to chew gum. I first checked with her nurse and was told it was OK. So I went downstairs and purchased her some. She began to complain of pain again. The nurse was called. I stayed with her until she began to fall asleep. (I made sure she did not have any gum in her mouth during this time.) Then I left. I plan on seeing her again today.

Our former doula patient Ms. P. called me Sunday evening. She was transferred to a rehab facility in Sherman, Texas, about 1½ weeks ago. She is doing fine, says it is a nice facility and the staff is working with her. She gets therapy twice a day, and she says her eating has increased. Her family has been visiting her. Her tone was upbeat and positive. Marci, to me personally, this is a true success story from where I sit. I first met Ms. P. in the intensive care unit in major pain, intermittently coherent, and in a fetal position. Over the weeks she voluntarily told me about her past health history problems and also about what she described as “a lack of care” and “the fear of dying from lack of care” in a Sherman, Texas, hospital. During her stay at Baylor, I witnessed the care she received from the Baylor staff, their interaction with her and with me. I realize there may be tough roads ahead for her, and the possibility that she may not ever be completely healed, but I will continue to pray for her. I personally witnessed my Lord and Savior at work, as he worked relentlessly to save this woman’s life. I can honestly say that Baylor is “a great humanitarian hospital, one to which men of all creeds and those of none may come with equal confidence” [quote from hospital founder, George Truett].

If you would like to learn more about this valuable volunteer opportunity or are interested in starting a Doula to Accompany and Comfort Program in your hospital or facility, please contact the Rev. Marci Pounders or Amy Levine:

- Rev. Marci Pounders, Chaplain and Bereavement Coordinator, Supportive and Palliative Care Service, Baylor University Medical Center at Dallas, 3500 Gaston Avenue, Dallas, Texas 75246 (e-mail: marcip@baylorhealth.edu).
- Amy Levine, MSW, LMSW, LCSW, Director, Doula to Accompany and Comfort Program, Jewish Board of Family and Children’s Services, 135 West 50th Street, New York, New York 10020 (e-mail: alevine@jbfcs.org).

It is advisable for new programs to be affiliated with the Doula to Accompany and Comfort Alliance/Jewish Board of Family and Children’s Services in New York.